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ABSTRACT

This document reports on the threat of HIV/AIDS to young people in the United States and proposes ways in which the Federal government could further address the needs of adolescents. Analysis of data gathered from young people affected by the HIV/AIDS epidemic and from professionals engaged in HIV research, prevention, and care revealed several trends: (1) one in four new HIV infections in the United States is estimated to occur among people under the age of 21; (2) HIV/AIDS does not discriminate by gender, geography, or sexual orientation; (3) efforts must be made to communicate to young people that the decisions they make now can affect them for the rest of their lives; (4) unless education and prevention programs are made available and accessible to young people they will continue to be at risk for HIV; (5) the lack of access to HIV counseling and voluntary testing for young people is a major barrier to prevention and treatment; (6) adolescents must become a bigger part of the research process; (7) young people are an important resource in the national response to this epidemic; and (8) the methods and goals established by the Federal government to address the HIV/AIDS epidemic can serve as an example for states, regions, and communities. Sections of the report discuss the AIDS epidemic: prevention; testing, treatment, and care; research; and suggested steps for the Federal government to take to combat the epidemic. (ND)

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YOUTH & HIV/AIDS: AN AMERICAN AGENDA

A REPORT TO THE PRESIDENT

U.S. DEPARTMENT OF EDUCATION
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Prepared by the
Office of National AIDS Policy
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March 1996

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THE WHITE HOUSE

WASHINGTON

March 5, 1996

Dear Mr. President,

Today, one-quarter of all new HIV infections in the United States are estimated to occur in young people between the ages of 13 and 21. That means at least one American under the age of 21 becomes infected with HIV every hour of every day. The rate of infection among young people are growing as the epidemic spreads into suburban communities and the nation's heartland.

It is heartbreaking to see another generation of our Nation's young people fall prey to this epidemic.

At your direction, the Office of National AIDS Policy has prepared this report, "*Youth and HIV/AIDS: An American Agenda,*" an examination of the current state of the impact of HIV and AIDS on America's young people and a series of actions that can be taken to reverse these very troubling trends.

While progress has been made since this epidemic began, this report underscores a crying need for public and private sector institutions to work together even more vigorously on new prevention, treatment, and care strategies for youth.

This report is the result of a unique collaborative effort of the public and private sectors sponsored by the National AIDS Fund and underwritten by the Until There's A Cure Foundation and James C. Hormel. This office is especially grateful to a team of young people who played a critical role in collecting information and ideas —- Miguel Bustos, Alex Danford, Michele Kofman, and Mangierlett Williams.

I will be sharing these findings widely with national and community leaders and with the thousands of young people who have already become involved in AIDS prevention, treatment, and care.

As you said in your remarks to the White House Conference on HIV and AIDS, we all have a responsibility to make sure that young people "know we care about them and we want them to have a future." It is my hope that this report will begin a process that helps us reach that goal.

Sincerely,

Patricia S. Fleming

Patricia S. Fleming
Director, Office of National AIDS Policy

Executive Summary

Youth and HIV/AIDS: An American Agenda

This report is neither a set of new recommendations nor a list of new ideas. It is intended as a catalyst of change in the way Americans view the threat of HIV and AIDS to the next generation.

This report was requested by President Clinton and written after numerous interviews were conducted with young people who are affected by this epidemic as well as professionals who are engaged in HIV research, prevention, and care. What they said, and what is outlined in this report, is that even though progress has been made, this nation must increase its commitment to greater understanding, education, communication, research, and care to bring an end to this tragic disease among America's youth. Until then, adolescents across America will continue to be infected and affected by HIV and AIDS at troubling rates.

One in four new HIV infections in the U.S. are estimated to occur among people under the age of 21.

An estimated 40,000 to 80,000 Americans become infected with HIV each year, or an average of 110 to 220 a day. Under current trends, that means that between 27 and 54 young people in the United States under the age of 21 are infected by HIV each day, or more than two young people every hour. A significant number of young people are engaging in sexual intercourse as well as drug and alcohol use at earlier stages in their lives. This fact, coupled with the disturbing number of adolescents who are prone to high risk behavior due to homelessness, sexual abuse, and other circumstances, places young Americans in a situation that leaves them extremely vulnerable to HIV infection. Experts expect this high rate of infection to continue unless a greater commitment to HIV prevention is made by young people themselves, their families, their educational and cultural institutions, their religious institutions, and their peers.

HIV/AIDS does not discriminate by gender, geography, or sexual orientation.

In the nearly 15 years since the first cases of AIDS were reported in the U.S., the epidemic has spread across the country. Cases have been reported in every state, Puerto Rico, the District of Columbia, and the American territories. Earlier concentrations in urban centers have given way to waves of cases in suburban and rural communities. Young gay men -- especially young gay men of color — remain at very high risk for HIV. Young women are also at an increased risk both biologically and behaviorally.

A concerted effort must be made by parents, community leaders, policy makers, schools, and young people to communicate to America's youth that they have worth and that the decisions they make now can affect them for the rest of their lives.

Reaching out to those who are most at-risk -- gay and lesbian youth, homeless and runaway youth, those in families with lower socioeconomic status, those who have lost a parent to AIDS, those born HIV positive, and illiterate adolescents -- and communicating these important messages can mean the difference between life and death. Homophobia in the design and implementation of AIDS prevention programs drives away many gay and bisexual adolescents from needed information and care.

Unless education and prevention programs are made available and accessible to young people they will continue to be at risk for HIV.

While many adolescents are aware of HIV/AIDS, enough information is not available to them on how to prevent infection and spread of the disease. Education on HIV/AIDS prevention should begin at an early age and be continually reinforced both in and beyond the classroom. Educational programs and preventive messages need to be developed and delivered by parents, teachers, religious leaders, youth leaders, professionals working with adolescents, peers, media, and role models. Young people themselves -- serving as peer educators -- need to be enlisted and relied on as an important part of the prevention effort.

The lack of access to HIV counseling and voluntary testing for young people is a major barrier to prevention and treatment.

In some areas, there is a clear lack of access to voluntary and confidential HIV counseling and testing for young people. Lack of insurance, parental consent laws, personal finances, and transportation logistics are all barriers to access. Enhanced education programs need to include information on how a young person can receive appropriate counseling and testing for HIV. The nation's health care system needs to incorporate HIV prevention information for young people into consumer education programs and provide adequate financial coverage for young people who test positive for HIV.

Adolescents must become a bigger part of the research process.

Adolescent treatment approaches may vary from those used for adults or infants. Because little definitive research has been conducted to date with HIV-positive adolescents, the specific impact of puberty on the course of HIV infection has not yet been determined. Behavioral trends that play a key factor in treatment and prevention have also not been sufficiently studied. Barriers to more age-appropriate treatment research include the difficulties in enrolling young people in research programs and insufficient long-term funding for this research.

Young people are an important resource in the Nation's response to this epidemic.

Government, medical, and community leaders can learn a great deal by listening to the voices of young people as they articulate their needs for understanding, education, communication, and research. Young people must become more involved in our response to the epidemic and help each other understand the scope of this epidemic. They must work together with the nation'sleaders to overcome a disease that threatens all our futures and the future of our country.

The goals the Federal government has established to address the epidemic of HIV/AIDS affecting the youth population, and the methods that have been set forth to achieve them, can serve as an example for states, regions, and communities across the nation.

The Federal government can further address the needs of adolescents affected by HIV/AIDS in the following ways:

♦ Prevention programs increasingly address the needs of young people. The Centers for Disease Control and Prevention has established the Prevention Marketing Initiative and an ambitious broadcast and print public service effort focused on HIV infection in young adults. Young people and their advocates should be included in all HIV prevention community planning councils to provide their perspective on how to best address their needs for prevention programs at the local level.

♦ The Department of Health and Human Services should create a forum of young people who are infected or affected by HIV as well as their parents, advocates, and health care providers to report to Federal officials and help identify and articulate the needs of adolescents in fashioning Federal responses to HIV and AIDS.

♦ The Health Resources and Services Administration should encourage the inclusion of young people and their advocates on AIDS care planning councils to help identify local needs and ways to target Federal funds to help meet the distinct developmental and comprehensive care needs of youth.

♦ The Centers for Disease Control and Prevention (CDC) should encourage the inclusion of young people and their advocates in AIDS prevention planning councils to provide their unique perspective of the needs of youth in prevention efforts.

♦ The Federal government should continue to help the nation's schools and other youth serving agencies implement comprehensive programs to prevent the spread of HIV among young people.

♦ The National Institutes of Health and the Food and Drug Administration should continue to encourage the enrollment of adolescents in government and industry sponsored HIV/AIDS clinical trials.

♦ The Public Health Service should work with the researchers, clinicians, medical community, and patients to develop appropriate clinical practice guidelines for adolescents with HIV/AIDS.

♦ In releasing data from clinical trials, NIH and FDA should include specific data related to adolescents. In those cases where the number of adolescents participating in a trial is too small, anecdotal data should be released on a limited basis to allow clinicians anopportunity to begin building a base of information for their use in treatment.

♦ The Federal government should support expanded access to testing and counseling for young people. The CDC guidelines for testing and counseling should address the special needs of adolescents, such as developmental issues, processes for consent, confidentiality, and payment for services. As part of a grant application for counseling and testing funding, states should demonstrate the availability of testing and counseling services for young people.

♦ The Substance Abuse and Mental Health Services Administration (SAMHSA), the Centers for Disease Control and Prevention (CDC), and the Health Resources and Services Administration (HRSA) should collaborate on substance abuse treatment and prevention strategies affecting adolescents to ensure a coordinated effort.

PREFACE

We are four 25-year-old people who carry many labels: white, black and Latino; male and female; straight and gay; HIV positive and HIV negative. We are from different religious backgrounds and different parts of the country. There are more things that distinguish us from one another than make us similar. Yet, at our core, we are young people who have been affected or infected by HIV and AIDS, and we are deeply troubled by what the future may hold for us and our generation.

More than seven million people in the world between the ages of 15 and 24 have been infected with HIV. Many of them have already died. Our generation has inherited an epidemic that is killing our parents, friends, and loved ones, teachers, doctors, and role models.

In helping to prepare this report, we heard the voices of young people who are living with HIV/AIDS. We heard from their friends, their caregivers, their parents, and their families. Facts and figures help us understand the scope of the epidemic, but it is these voices that help all of us understand the pain, the frustration, and the suffering that so many young people are experiencing due to HIV and AIDS.

We set out to examine the impact HIV and AIDS have had on America's young people. We spoke with young people whose lives have been touched by AIDS; with public health professionals engaged in HIV prevention, treatment, care and research; and with activists advocating for change. Each encounter brought us face-to-face with the realities of HIV and AIDS in the lives of young people.

We have met young people who are fighting for their lives and dealing with issues that most Americans cannot imagine at such an early age: their own mortality. We have also seen the fear and helplessness in the faces of young HIV-negative people who have grown up in the shadow of AIDS. And we have seen the tremendous courage of those living with HIV and AIDS who have used their own experiences to educate and protect their peers.

Our experiences are not unique and these stories are not new. For more than a decade, concerned professionals and policy makers have sought ways to address the threat that HIV and AIDS present to our nation's young people. Hearings and conferences have been held; reports have been written and distributed; promises have been made. But not all of those promises have been kept and it is time to sound an alarm.

We are running out of time. HIV is cutting a deadly path through the future of this nation. It does not respect nationality, social class, or sexual orientation. It has invaded this nation's cities, suburbs, and rural communities.

We cannot protect young people through ignorance. We cannot protect young people by denying that they are inquisitive, sexually active, or given to experimentation. They and we are all these things. Yet, with education, information, and skills we can protect young people and prevent the spread of HIV.

It is our hope that this report will open the hearts and minds of policymakers, parents, leaders, and young people. With strong leadership, a shared commitment to action and personal responsibility, and a compassionate nation we can -- once and for all -- stop this epidemic in its tracks.

We thank President Clinton for his leadership in the battle against AIDS and his willingness to focus on this controversial subject. We also thank Patsy Fleming for reaching out to young people for their ideas, their voices, and their leadership.

Miguel Bustos, San Francisco, CA
Alex Danford, Dayton, OH
Michele Kofman, New York, NY
Mangierlett Williams, Washington, DC

Part I

A GENERATION AT RISK

Today's youth are tomorrow's future. Yet, every year in the United States half of all new HIV infections occur among people under the age of 25 and one-quarter of new infections occurs among people between the ages of 13 and 21. Based on current trends, that means that an average of two young people are infected with HIV every hour of every day.

While the number of cases of AIDS among teenagers is relatively low, it has grown rapidly from one case in 1981 to 417 cases in 1994. The rate of HIV infection among teenagers becomes more apparent when you examine the number of AIDS cases among people in their 20s. According to the Centers for Disease Control and Prevention (CDC), one in five AIDS cases in the U.S. is diagnosed in the 20-29 year age group. Looking at AIDS cases alone obscures the extent of the epidemic among young people. Since a majority of AIDS cases are likely to have resulted from HIV infections acquired 10 years before, most of these individuals are likely to have been infected as teenagers.

> *"It is one of the joys of childhood that children think they will live forever. It is one of the curses of childhood in some of our meanest neighborhoods that children think they won't live to be much beyond 25 anyway. In a perverse way, both of those attitudes are contributing to the problem, because one group of our children think that they are at no risk because nothing can ever happen to them — they're bulletproof. Another group believes that no matter what they do, they don't have much of a future anyway. And they are bound together in a death spiral when it comes to this. This is crazy. We have got to find some way to tell them you must stop this." — President Clinton, December 6, 1995, to the White House Conference on HIV and AIDS.*

Among adolescents (13-19 years of age), HIV infection is more prevalent among those in their late teens, males, and racial and ethnic minorities. But recent trends also point to a rise in infection and diagnosis among adolescent females -- increasing from 14 percent of diagnosed cases of AIDS among adolescents in 1987 to 43 percent in 1994.

What is also clear is that American adolescents are engaging in behaviors that put them at risk for acquiring HIV infection as well as other sexually transmitted diseases, unintended pregnancy, and infections associated with drug injection. According to the CDC, approximately three-quarters of high school students have had sexual intercourse by the time they complete the twelfth grade. About 50 percent of sexually-active high school seniors report consistent use of latex condoms and surveys indicate that condom use declines with age. In a recent survey, one in 62 high school students reported having injected an illegal drug. Recent reports indicate an increase in the use of non-injectable drugs, including marijuana, cocaine, and alcohol. The use of alcohol and other drugs impairs judgment and can lead to risky sexual behaviors and practices, particularly for young people in the stage of experimentation.

Also according to the CDC, about 12 million cases of sexually transmitted diseases (STDs) are reported in the U.S. each year. Roughly two-thirds of those cases are reported in individuals under the age of 25 and one-quarter are among teenagers. About 3 million teens contract an STD each year, and many of these young people will suffer long-term health consequences as a result.

Without forceful and focused action, these already troubling trends may worsen. This is a particularly complex challenge. Adolescents are neither large children nor small adults, yet they often are treated as one or the other

and their unique characteristics and needs are often overlooked. Adolescents are in a developmental stage that can make them particularly vulnerable -- both physiologically and emotionally -- to activities that put them at risk of becoming infected with HIV.

Young people are at greatest risk of HIV infection if they have unprotected sex outside of a mutually monogamous relationship between two HIV-negative individuals, use injection drugs, or use alcohol or other drugs that impair their decision-making abilities. Adolescents often do not have the maturity, experience, or range of options that adults usually bring to their decision-making processes. Adolescents are engaged in a developmental process that includes development of decision-making skills, sexual maturation and experimentation, emotional and cognitive changes, and the molding of identity and self-worth.

Adolescents live in a world in which their families, cultural institutions, religious institutions, media, and peers compete to instill values, dictate actions, and impart positive and negative messages to them. The mass media often glamorizes youth and sex at the same time that parents and schools are encouraging abstinence. Attempts to turn young people into sex symbols are particularly troublesome because of the message that sends to both young people and adults.

"If you're going to educate kids about AIDS, you have to educate them about drugs as well. If you're a youth, you're going to experiment with drugs, especially if you live in a metropolitan area. Even though you get stupid with drugs, you still think about things you don't want to do, but you do it anyhow." — 16-year-old HIV-positive youth from San Francisco.

Adolescents, particularly those in their early teens, tend to be short-term thinkers. To many, the present is all important and the future often is perceived in very vague terms. Some adolescents, then, feel invulnerable to harm and often make decisions based on immediate desires rather than after consideration of the long-term consequences of their decisions.

Many young people have an enhanced sense of invincibility and may be unprepared to respond to situations that place them at risk. They may not perceive a need to avoid the risk or be aware that certain behaviors can place them at risk for contracting HIV. At the same time, many young people experience stigmatization and discrimination because of their race, ethnicity, gender, sexual orientation, HIV status, or economic status. Such discrimination hampers their ability to navigate successfully the many challenges and complex situations that they confront.

Set against this backdrop is the fact that young Americans are beginning the physiological and emotional process of puberty earlier in their lives than did previous generations. Yet they are alsopostponing many traditional adult responsibilities including full-time employment, marriage, or a committed monogamous relationship.

All young people need thoughtful guidance and loving care. The role of parents has never been more important in the successful development of adolescents. But it is a job that has also become much tougher. Parents, too, need assistance in learning how to best communicate with their children about the often difficult subjects of sex, drug use, and death. Many adolescents do not have adults in their lives who can effectively provide the nurturing and guidance that they need.

Some young people are at particular risk of HIV infection due to circumstances that are often beyond their control. Adolescents who are victims of sexual abuse are at risk for direct transmission from their sexual partners and may also suffer emotional problems that lead them to later engage in high-risk behavior that can lead to HIV infection.

There are also those youth who have left or been kicked out of their homes or who have fled abusive family relationships. They are highly susceptible to risky behavior just to survive. Their sense of self-worth is usually low or non-existent. They may trade sex for food, housing, drugs, and affection. Adolescents challenged with homelessness rarely view reducing their risk factors for HIV as a high priority in comparison with their daily struggle for survival.

Gay, lesbian, and bisexual youth often are isolated from positive adult role models and peers. Personal, institutional, and societal homophobia can often deny them access to opportunities to address their developing sexuality and contribute to a feeling of worthlessness.

Adolescents need the tools to successfully navigate an increasingly dangerous world. Young people need to hear from parents and other adults that they are loved, valued, and have worth as individuals so they will internalize those feelings and believe they are worth protecting. They must be shown the dangers they may encounter and taught negotiation and decision-making skills. They

need to be engaged in activities that will allow them and their peers to practice those skills. And they need to exert personal responsibility to protect both themselves and others from infection.

Adolescent HIV prevention is a job too big for any one segment of society. All parents, adults, leaders, policy-makers, young people, and institutions must become constructively engaged in the important work of preventing HIV infection among our nation's most precious resource.

"We grow up hating ourselves like society teaches us to. If someone had been 'out' about their sexuality. If the teachers hadn't been afraid to stop the 'fag' and 'dyke' jokes. If my human sexuality class had even mentioned homosexuality. If the school counselors would have been open to a discussion of gay and lesbian issues. If any of those possibilities had existed, perhaps I would not have grown up hating what I was. And, just perhaps, I wouldn't have attempted suicide." — Kyallee, 19.

Part II

PREVENTION

Until a vaccine is found, the only way to prevent new HIV infections is through education. Adolescents can protect themselves if they are given comprehensive information and the tools, skills, and reasons to use them. It is incumbent on all adolescents to demonstrate personal responsibility by protecting themselves and others. Communities promoting the close cooperation of parents, teachers, coaches, clergy, physicians, and other adults interacting with youth can ensure that every young person has access to this information. Every adult who touches a young person's life should be equipped to impart this knowledge in a clear, accurate, sensitive manner.

Parents can be the best teachers for their children and HIV prevention approaches for adolescents should ideally start with parents. Parents should be key participants in HIV prevention efforts. If parents aren't convinced of the risk to their children, they may fail to recognize their child's risk-taking behavior. More must be done to educate the parents of adolescents about the risks their children face and about the means that are available to protect their children from this disease.

"People say HIV is this or that group's problem, not mine. But for HIV, it's a matter of risk behaviors, not risk groups. Because if you say it's a risk group thing, I don't identify with that group, so I'm not at risk. That makes people feel invincible to HIV." — HIV-positive youth.

Efforts to encourage sexual abstinence should continue to be supported. Teens who are thinking about becoming sexually active should be encouraged to consider the implications of their decision and to examine whether they are prepared to deal responsibly with these behaviors (including taking personal responsibility for the consequences of these behaviors and protecting themselves and their partners against disease and unintended pregnancy). It is important that young people make healthy and safe choices about sex. To help them make those decisions, families and communities should help their young citizens to grow and develop to their full potential and provide them with a safe environment to accomplish that growth through schools, role models, and other opportunities. Without community support and reinforcement, even the best HIV prevention approaches will falter or fail.

Effective HIV prevention is neither a single program nor a single event; it must take place over the course of many years and be developmentally appropriate. Therefore, it is inadvisable to separate HIV prevention from sexually transmitted disease prevention, pregnancy prevention, substance abuse prevention, sexuality education, self-esteem activities, and human development education.

National Institutes of Health programs on adolescent risk behavior and HIV infection include programs to identify and develop potential intervention strategies for decreasing the high-risk behaviors of young people. Model programs are being developed to increase adolescent STD/HIV prevention knowledge, improve attitudes, and develop skills to delay adolescent sexual activity. Many of these programs are developing and testing culturally sensitive and gender appropriate interventions that target the reduction of AIDS risk behaviors among diverse groups of adolescents. Some of these interventions have already produced positive behavior change among homeless and runaway youth.

Successful prevention efforts concentrate on providing access to accurate information, personalizing this information to motivate change, providing training in behavioral skills for implementing decisions, and reinforcing and rehearsing skills to build competence, communication, and self-esteem. Reality-based approaches recognize that people sometimes use faulty judgment and incorporate efforts to emphasize the ability of individuals

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to recommit to their long-term goals.

Schools are a highly effective and appropriate place to teach young people HIV prevention information and skills before they begin the behaviors that put them at risk for HIV infection. An estimated 98 percent of young people between the ages of 5 and 17 are enrolled in schools. The Centers for Disease Control and Prevention (CDC) has implemented a multi-faceted program to help schools and other agencies that serve youth across the nation provide effective health education to prevent the spread of HIV. This program is based on the principle that the specific scope and content of HIV education in schools should be consistent with parental and community values. CDC provides funding and technical assistance to the departments of education in every state, six territories, and 18 large cities. CDC also has developed "Guidelines for Effective School Health Education to Prevent the Spread of AIDS.

"We, the young people of this country, need a place where we can go to ask our questions, where we won't be teased or ridiculed. We need a place where we can ask about our mixed up feelings, about sex, and about AIDS." — 15-year-old high school student from Concord NH.

Beginning at the earliest appropriate age, young people should receive sexuality and HIV/AIDS education as part of a comprehensive curriculum of health education. Such a curriculum should include accurate information about HIV and modes of transmission, the opportunity to assess personal risk of infection, and skills training. HIV prevention information should be age-, language-, and culturally-relevant and designed to accommodate the context of the lives of young people and their families.

There is a compelling need for comprehensive school-based HIV prevention education, yet those school-based efforts are just one step in a long journey to effectively protecting adolescents from HIV. School-based programs do not reach all youths at risk. Those adolescents not in school -- because they have graduated or dropped out -- will need to be reached with the same kind of basic information that schools provide to all others.

Misconceptions and misunderstandings about HIV transmission and high-risk behaviors often arise when relevant information is omitted. Sexuality education, when done properly, reflects the needs of the community and acknowledges the value of both abstinence and safer sex as tools to prevent HIV infection. Yet in some school districts, education policies preclude discussion of subjects such as intercourse, homosexuality and bisexuality, and condom use. Discussion of the facts concerning such matters is not inconsistent with also encouraging abstinence or delayed sexual activity.

The job of HIV prevention is too important to be left to health educators alone. As mentioned before, all adults who work with young people should be armed to impart HIV prevention information effectively and sensitively to adolescents in their charge. This requires approaches that work -- those designed to work well in a given community -- and that can be employed to meet a variety of prevention needs.

Yet, teaching young people something and ensuring that they will follow through with what they've been taught are two separate things. To be successful, HIV prevention efforts must be targeted and they must be sustained. Lessons learned from efforts to prevent smoking, substance abuse, and teenage pregnancy demonstrate that such efforts can positively affect adolescents' behavior.

In 1994, the Centers for Disease Control and Prevention (CDC) launched the Prevention Marketing Initiative (PMI), a comprehensive HIV/AIDS education and prevention program involving partnerships between Federal, state, and local government and national and community-based organizations throughout the U.S. The PMI specifically targets young adults between the ages of 18 and 25. In 1994 and again in 1995, CDC prepared and distributed public service announcements aimed at young adults that communicate two central messages. First, sexual abstinence or delaying sexual activity is the most effective way to prevent sexual transmission of HIV. Second, for those who are sexually active outside of a mutually monogamous relationship, the correct and consistent use of latex condoms is an effective method of preventing HIV transmission.

Successful HIV prevention efforts also have recognized that behavior isn't changed with knowledge alone. An analysis of approaches that are successful in reducing high risk behavior among young people found that schools often were at the focal point of these efforts and that community-wide, multi-agency efforts were needed both in terms of funding and reinforcement of messages. Successful prevention efforts also have been designed to meet the specific needs of target audiences and offer their services outside the traditional school-based setting.

Community-based organizations are also a valuable and credible source of prevention messages. They can supplement, support, and reinforce messages from within families and schools.

Peer counselors -- young people trained in providing HIV/

AIDS-specific information -- have been shown in NIH-sponsored studies to be particularly successful messengers. Peer educators have repeatedly demonstrated that they can present material in a way that addresses the relevance of HIV and HIV prevention to young people's lives. Adolescents often find prevention messages more believable when they are delivered by their peers.

Peer-led prevention efforts are currently being conducted at a variety of sites around the country but many more such efforts are needed. The challenge lies in supporting the development and application of programs that are innovative and address the needs of adolescents.

"If I could talk to the President, or a Senator, or anyone in the Federal Government who can make a difference, I'd tell them to take a look, learn a lesson from the youth that are currently dealing with the disease. Listen to them, hear their stories and then see that they have a future. If they don't have that future, then we won't have an America." -- Allan, San Francisco.

Part III

TESTING, TREATMENT AND CARE

Advances in science and medical care have enabled individuals living with HIV to live longer, healthier lives. Drugs and treatments now are available to arrest or even prevent opportunistic infections that previously led to death. New classes of drugs now in development may hold promise for dramatic improvements in life expectancy and quality of life. However, in order to access such care, individuals must know their HIV status and be connected to a continuum of care.

Millions of young people who have engaged in high-risk behaviors do not know their HIV status. Adolescents should be strongly encouraged to learn their HIV status. A negative test provides the best opportunity to reinforce the importance and efficacy of risk-reduction behaviors. A positive test provides an immediate opportunity to link those who are HIV-positive to treatment, often at an early stage of disease progression. Such early intervention has been shown to be highly effective at prolonging and improving quality of life.

In 1994, the Centers for Disease Control and Prevention (CDC) supported HIV counseling and testing services in approximately 9,600 sites throughout the U.S. Those sites accommodated approximately 400,000 visits by persons 19 years of age or younger. Many of those services are provided at little or no cost to youth with parental permission. In addition, the CDC supports the National AIDS Hotline and the National AIDS Clearinghouse, which provide referral and information services through toll-free telephone services. Both are private, free, and confidential and are well publicized.

HIV testing should always include appropriate pre- and post-test counseling to ensure that both HIV-negative and HIV-positive young people understand their status and their responsibilities to themselves and others as a result of that status. Pre- and post-test counseling is particularly important for adolescents. Counseling should be appropriate for the adolescents' social and emotional development, language, culture, and sexual orientation. Effective counselors are sensitive to the great anxiety adolescents feel about HIV testing because of fear of the disease as well as the stigma attached to the disease. As with prevention efforts, the use of peer educators in pre- and post-test counseling has been shown to be effective in communicating critical information to adolescents at what is often a highly emotional point.

The process of testing for HIV allows adolescents to evaluate their own behavior and think of the consequences of that behavior. As a result, there are numerous emotional needs that must be dealt with by both adolescent and counselor if the effort is to be a success. The involvement of parents and other family members is critical to an HIV-positive youth's ability to cope with this diagnosis and enter into a continuum of care.

> *"I go to a free clinic that I feel really comfortable in. It's really family-oriented. The people are really caring, and they all know me. When I was 19, I took the HIV test on a whim. I really didn't expect a positive result. But that's what it was. Everybody working at the clinic cried." — Ayisa, 20, New York.*

Whether the results are positive or negative, post-test counseling is equally important. For adolescents who test negative, post-test counseling provides an opportunity for further risk reduction. For some, this may be the only opportunity for meaningful prevention education. Positive results require immediate intervention. It is essential that adolescents have an opportunity to talk to knowledgeable persons who can help them understand what their HIV status means and help them deal with issues that may seem overwhelming. HIV-negative youth should have that behavior reinforced.

Adolescents' access to HIV counseling and voluntary testing often is severely limited by a variety of factors. First, many adolescents don't know how to arrange for HIV testing and where to go for such services. Second, adolescents

do not have the money or means of transportation necessary to access some forms of counseling and testing. Third, school hours often coincide with the hours of counseling and testing facilities. Finally, parental consent requirements for counseling and voluntary testing also may pose a barrier for many young people -- especially those who know or feel they cannot communicate openly with their parents about this subject.

Taken singly, these barriers can make it difficult for an adolescent to get counseled and tested. Combined, they present a formidable barrier that only a truly determined adolescent can surmount.

To address some of these concerns, HIV counseling and voluntary testing sites need to be designed to be accessible to adolescents. Business hours should complement rather than compete with school schedules and facilities should offer their services at low or no cost to adolescents. This would accommodate adolescents who don't own a car and must use public transportation, are in school and involved in extra-curricular activities, and have little money or independent health insurance.

"I was infected with HIV by my first partner when I was 16 years old. Now at 20 I have this virus that's taking my life because everything I heard when I was younger was sugar coated. We need more complete information than what we are being given. Even the pamphlets concerning HIV/AIDS prevention are too basic and bland. We need to know real stuff." -- Ryan, age 20.

A particularly challenging impediment to counseling and testing is the legal requirement in many states for parental consent. Consent is usually necessary for medical care of individuals under the age of 18. The conditions under which minors may consent to HIV testing vary across states. Ideally, parents, young people, and health care providers should all possess the skills and knowledge necessary to maximize a youth's access to services and support. However, consideration should be given to creating alternative access to counseling and testing where obtaining parental consent is not possible.

Linking HIV-positive adolescents to a system of HIV primary care immediately after a positive diagnosis is vital in order to prevent or delay the onset of HIV-related opportunistic infections, such as Pneumocystis carinii pneumonia (PCP), and to prolong the healthy lives of HIV-positive individuals. An integrated care system, in which medical services are connected to mental health, substance abuse, education, juvenile justice, and social support is necessary to meet the needs of these adolescents. For runaway or homeless youth, housing and nutrition services are also critical. Currently, there are few programs that meet the full range of health care needs for HIV-positive youth. Efforts are plagued by insufficient numbers of primary care physicians and other health care providers specifically trained to work with adolescents, lack of insurance and other financial assistance, a fragmented health care system, and geographically remote facilities. NIH is supporting programs to identify better ways of facilitating access, utilization, and adherence to medical, mental health, and substance abuse treatment by adolescents.

Large numbers of young people are uninsured or underinsured, and the sources for funds to pay for necessary services are limited. If an adolescent is HIV-positive access to insurance often is blocked by insurance policies that exclude individuals with pre-existing medical conditions.

Federal grants for program development such as the Health Resources and Services Administration's Ryan White CARE Act, including Special Programs of National Significance (SPNS), have encouraged care models that consider the special needs of the adolescent population and provide communities with the tools they need to conduct effective outreach programs. Title IV of the Ryan White CARE Act provides support for the development of innovative models that link systems of comprehensive primary/community-based research, medical, and social services for children, adolescents, and families.

Besides responding to an HIV-positive adolescent's physical and mental health needs, linkage with important social services is also an important element to care. Social service providers should be trained to offer referrals for legal assistance, other treatment programs, information about housing, job-training assistance, and help in obtaining health insurance. They also are more able to offer outreach services for adolescents who are homeless, pregnant, or trading sex for food and shelter.

Medicaid provides coverage for a comprehensive set of benefits that includes counseling and testing, prescription drugs, physician visits, inpatient hospital care, substance abuse treatment, home care, and hospice care. Medicaid coverage of children and adolescents has been improved in recent years but many low-income families may not be aware of their eligibility for such benefits. The Federal government and states should examine opportunities to ensure that all Medicaid-eligible HIV-positive youth have access to appropriate treatment and care. Medicaid is the largest single payer of direct medical services for people living with AIDS, serving nearly 50 percent of all persons living with AIDS and more than 90 percent of children with AIDS.

Part IV

RESEARCH

HIV/AIDS research has made great strides on many fronts. Physicians have a growing array of medications to treat and even prevent a variety of HIV-related opportunistic infections. As a result, HIV-positive people who have access to care usually are not getting sick as often, their illnesses aren't as severe, and they are spending less time in the hospital than they did 10 years ago. But adolescents have not received the full benefit of recent research discoveries, and there is significant unmet need for adolescent-specific treatment and behavioral research. We clearly do not know enough about adolescents in general, about how HIV affects them physiologically or behaviorally, and about the progress of HIV disease in young people.

HIV/AIDS research efforts have primarily focused on two specific populations: infants and adults. Funding for adolescent-related AIDS research has traditionally come from those pursuing pediatric research. But adolescents are biologically more like adults than infants yet they still are not at the same developmental stage as most adults.

Adolescents are not considered central to the pediatric mission, and researchers who focus on adults usually are not funded to include adolescents in their research programs. The result has been that adolescents appear only peripherally on the radar screens of most AIDS researchers, and when they do, it's only to the extent that they share adults' physical or behavioral traits.

Additionally, a variety of developmental and behavioral factors challenge efforts to draw adolescents into the few adolescent-specific protocols that have been developed for their benefit. Adolescents can sometimes be particularly challenging subjects for research. Researchers have reported difficulty enrolling adolescents in protocols, keeping them enrolled, and ensuring that they are following the guidelines for protocol conduct.

> *"I'm HIV positive. I'm a teenage mother. I'm affected by my community. How do you expect me to live? Where is my future leading? Where is the future leading for my 3-year-old daughter?" — "Haitien"*

Basic research sponsored by NIH has provided and will continue to provide a better understanding of the pathogenic mechanisms and course of the disease in adolescents.

In recognition of the fact that adolescent development is different from that of both adults and children, NIH is supporting studies on adolescents.

While NIH has opened pediatric clinical trials to adolescents up to age 18 and adults trials to those who are as young as 13, adolescents continue to face barriers to their participation in clinical trials. This lack of participation has left significant gaps in the knowledge base about adolescents. Scientists are quick to acknowledge that a great deal of catching up remains to be done. Basic research on adolescent reproductive and immune system development is lacking. Data are just beginning to be gathered on how the adolescent's immune system differ from that of adults, an important consideration in defining the response of an adolescent's body to HIV. Further studies are needed on the effect HIV has on adolescent growth and puberty.

Additional studies are needed to understand the natural history of HIV in adolescents as well as expanded study of youth and their behaviors. The NIH currently sponsors natural history studies designed to track the shifting demographics and the changing manifestations of HIV/AIDS. But there are things we need to know about HIV-positive adolescents that we don't know, such as how they become infected, how they effectively resist infection, how long they live, and how quickly they die. We don't know enough about the factors that influence the behavior of young people, including why some choose to be sexually active and others do not; why some use drugs or alcohol and others do not; and why certain sexual behaviors are chosen over others.

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Surveillance of HIV infection among adolescents in the United States has not been comprehensive enough to accurately estimate the scope of the problem. The family of HIV seroprevalence surveys should be expanded to target and teach us more about the epidemic as it affects young people. Accurate data help to target HIV prevention efforts and to forecast the kinds of services needed. Such studies would help to indicate which communities are experiencing high infection rates, how HIV is being transmitted, how long HIV-infected adolescents are ill, and the general scope of the epidemic among this age group.

The inclusion of adolescents in clinical trials permits the identification of appropriate regimens of treatment for this age group. The development of clinical practice guidelines with correct dosages and times to start treatment can only be developed from such studies. Similarly, the rapid dissemination of information concerning clinical practice guidelines, results of clinical trials, and options for trials, as well as eligibility criteria for trial participation, must be a high priority for the NIH.

There still is not enough information about the optimum time to begin anti-retroviral treatment, which treatments to use, and the correct dosages for adolescents. The lack of a significant base of adolescents enrolled in trials has resulted in little dissemination of information. At this early period in the study of adolescent-related HIV issues, even anecdotal information is important to clinicians and researchers if they are to begin building a response to the epidemic among young people.

The NIH has recognized that current research efforts aimed at young people are few in number and much further behind than those for adults and children. The Adolescent HIV/AIDS Research Network, a collaborative effort between the NIH and the Health Resources and Services Administration (HRSA), has been launched to plan and conduct research on the medical, biobehavioral, and psychosocial aspects of HIV and AIDS in young people. This network, combined with other youth-focused efforts at NIH and CDC, can reduce the barriers to young people participating in research and narrow the information gap. Working together the Federal government and its partners should achieve the goal of providing better treatments and health care to HIV-positive adolescents and crafting Federal responses that best meet their often changing needs.

Part V

FURTHER STEPS

This examination of youth and HIV revealed six common themes that require action at all levels of American society. There is strong consensus among scientists, educators, health care providers, community leaders, and young people themselves on these matters. They are:

♦ Young people, parents, schools, and communities must be integral partners in developing, delivering, and evaluating HIV prevention approaches for adolescents;

♦ Innovative, creative prevention efforts aimed at young people must be encouraged, adequately funded, and evaluated, and -- when found to be effective -- broadly disseminated;

♦ Comprehensive HIV/AIDS education — as part of comprehensive health education — should be available to all young people in all fifty states and U.S. territories;

♦ Routine counseling and voluntary HIV testing should be made more accessible, developmentally appropriate, and affordable to young people;

♦ HIV-positive adolescents should be linked to a continuum of care and services that will extend their life span and provide them with the information and skills they need to reduce the likelihood of further transmission;

♦ Adolescent-specific biomedical and behavioral research should be increased to enhance our knowledge of the progress of HIV disease in adolescents and of effective AIDS prevention approaches.

THE FEDERAL ROLE

The Federal Government has three central responsibilities in leading our country's battle against HIV and AIDS:

(1) Seeking a cure for those who are living with HIV/AIDS and a preventive vaccine to protect those who are uninfected;

(2) Helping communities cope with the financial costs of caring for those who are living with HIV/AIDS; and

(3) Working with communities to foster behaviors that prevent the spread of HIV.

During the past three years, the Clinton Administration has sought to fulfill these obligations by submitting budgets that would increase overall funding for AIDS-related programs by 40 percent. Funding for AIDS-related research has been increased by 26 percent and the Office of AIDS Research at the National Institutes of Health has been strengthened. Funding for AIDS prevention efforts has also increased and a new community planning process has directly involved local organizations in the design of prevention programs. Funding for AIDS-related care has increased by 90 percent, including a 108 percent increase in funding going to the Ryan White CARE Act. New efforts have been made to involve young people in each of these areas. The government has vigorously enforced provisions of the Americans with Disabilities Act prohibiting discrimination against people living with HIV and approval time for AIDS-related drugs has been cut in half.

In conjunction with this report, the following new initiatives should be undertaken:

Listening to the Voices of Youth. Young people should be encouraged and empowered to have a voice in the development and implementation of HIV/AIDS research prevention, and care efforts. The Federal government should take the following steps to assure that voice is heard:

♦ The Department of Health and Human Services should create a forum of young people who are infected with or affected by HIV along with their advocates and providers. This group should work with relevant federal agencies to help identify and articulate the needs of adolescents in fashioning Federal responses to HIV and AIDS;

♦ The Health Resources and Services Administration should encourage the inclusion of young people and their advocates on AIDS care planning councils to help identify local needs and ways to target Federal funds to help meet the distinct developmental and comprehensive care needs of youth.

♦ The Centers for Disease Control and Prevention (CDC) should encourage the inclusion of young people and their advocates in AIDS prevention planning councils to provide their unique perspective of the needs of youth in prevention efforts.

♦ The Federal government should continue to help the nation's schools and other youth serving agencies implement comprehensive programs to prevent the spread of HIV among young people.

Examining the Impact of HIV on Youth. Sufficient scientific information exists to indicate that HIV may behave differently in infected adolescents and that there are adolescent-specific health-care needs and treatment protocols that must be identified in order to respond effectively. The following steps should be taken to assure that this occurs:

♦ The National Institutes of Health and the Food and Drug Administration should continue to encourage sponsors to enroll adolescents, when feasible and appropriate, in HIV/AIDS clinical trials.

♦ In releasing data from clinical trials, NIH and FDA should include specific data related to adolescents. When the number of adolescents participating in a trial is too small, anecdotal data should be released on a limited basis to allow clinicians an opportunity to begin building a base of information for their use in treatment.

"The great burden we have as Americans is that when we have to deal with something new, too often we can't deal with it from imagination and empathy we have to actually experience it first. I do not want to wait until every single family has somebody die before we have a good policy on HIV and AIDS." -- President Clinton, December 6, 1995, to the White House Conference on HIV and AIDS.

♦ The Public Health Service should continue to develop in collaboration with researchers, clinicians, and the infected and affected community, clinical practice guidelines and expeditiously disseminate the latest information on state-of-the-art therapies, options for trials and eligibility criteria for entry into them, and health care and prevention techniques to U.S. and international communities affected by HIV/AIDS.

Making Informed Decisions. HIV counseling and voluntary testing provide an important bridge between HIV prevention and care. To assure that young people have access to such services, the following steps should be taken:

♦ CDC's counseling and testing guidelines should acknowledge and address the special needs of youth seeking such services. This guidance should address such issues as processes for consent, confidentiality, and payment for services. The guidance should be integrated into the training of all personnel at CDC-funded counseling and testing sites;

♦ CDC should require that, as part of the grant application for counseling and testing funds, states demonstrate the availability of counseling and testing for young people.

SHARED RESPONSIBILITIES

Any effort to protect young Americans from the threat of HIV and AIDS cannot begin and end with the Federal government. These Federal efforts should serve as the catalyst for action on all levels of society. Throughout the history of the epidemic, states, localities, communities, schools, churches, synagogues, private foundations, and voluntary charitable organizations have been actively committed to combatting the spread of HIV. These efforts should continue and should be expanded. The Federal government seeks and looks forward to a closer partnership with communities involved in this effort and pledges its continuing support for the critical work being done.

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The National AIDS Fund

The National AIDS Fund is the nation's largest philanthropic and grantmaking organization dedicated to eliminating HIV and AIDS as a major health and social problem. It works in partnership with communities to provide care and to prevent new infections through education, research, and outreach. Since it was founded, the Fund has provided almost $50 million to communities for HIV/AIDS programs, supporting more than 2,400 such programs in 31 states. The Fund also provides program and technical assistance for hundreds of national and local educational programs -- such as the Youth and HIV/AIDS Report -- and programs of direct service. The Fund also provides the nation's business community a network of leading corporate, government, and nonprofit experts who deal with HIV/AIDS policy issues, and it publishes a broad range of HIV/AIDS publications for both managers and employers.

The Until There's A Cure Foundation

The Until There's A Cure Foundation, principal funder of the Youth and HIV/AIDS Report, provides funding for innovative education programs to encourage safer behaviors among teens and young adults through peer-to-peer education. For those living with HIV/AIDS, the Foundation provides financial support for care and other services. For future generations, the Foundation supports AIDS vaccine development with funds being primarily contributed through the International AIDS Vaccine Initiative of the Rockefeller Foundation. Through partnerships with professional sports teams, the Foundation has reached audiences with its message of AIDS awareness. The Foundation was created by Kathleen Scutchfield and Dana Capiello, two mothers and entrepreneurs who have raised funds to support Foundation Initiatives through sale of The Bracelet, a 1/4-inch cuff bracelet featuring a familiar small raised AIDS ribbon.